

## Citizens' juries can bring public voices on overdiagnosis into policy making

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*Published in:*  
BMJ (Online)

*DOI:*  
[10.1136/bmj.l351](https://doi.org/10.1136/bmj.l351)

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*Recommended citation(APA):*

Degeling, C., Thomas, R., & Rychetnik, L. (2019). Citizens' juries can bring public voices on overdiagnosis into policy making. *BMJ (Online)*, 364, [l351]. <https://doi.org/10.1136/bmj.l351>

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**Title:** Citizens' juries can bring public voices on overdiagnosis into policy making.

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As practitioners and policy makers struggle to manage the risks and harms of overdiagnosis, **Chris Degeling and colleagues** contend that Citizens/Community Juries offer a way forward

Unnecessary and harmful interventions from overdiagnosis challenge the social and ethical contract that underpins healthcare.<sup>1 2</sup> Strategies to address overdiagnosis from population screening should engage with and consider public values and concerns.<sup>3</sup> Most high-income countries develop evidence-based policies to guide population screening using stringent criteria that are applied by expert panels to review the available technical evidence. Similarly, if perhaps not so systematically, expert panels collect and analyse pathophysiological and clinical evidence to determine disease thresholds and definitions.<sup>4</sup> But in both cases the final judgement as to the acceptability and legitimacy of different screening policies and disease definitions are informed by the values of the decision-makers, because the relative balance of harms and benefits of making changes are also subjectively weighed and valued.<sup>5-7</sup> Putting matters to the public promotes greater social and political engagement, public accountability and confidence in the decision ultimately made.

Public engagement occurs on a spectrum of participation in events that aim to consult the public (consumer forums/patient groups) to more formal deliberative methods such as citizens/community juries (CJs) that seek to bring lay-people into structured deliberation to address key complex problems (Textbox 1).<sup>8</sup> In this paper, we explore some of the advantages and limitations of using CJs to inform policy making in the complex policy areas of overdiagnosis.

**The value-add of convening CJs to consider screening and overdiagnosis**

In relation to overdiagnosis CJs have been primarily convened by health researchers, and as such should be viewed as providing research evidence for policy making that articulates values and explains the reasoning and preferences of an informed public. CJs are appropriate when the evidence is uncertain and there is disagreement as to its implications among experts, stakeholder groups, or both. For those charged with screening guideline development, CJs can help them understand why patients go against expert advice, and inform them of the factors that need to be explained and explicitly considered to retain public trust. CJs are designed to

allow participants to first be informed, and then to discuss, reflect and clarify their own views about the issue at hand rather than recording people's top-of-mind or intuitive reactions to contentious problems (like focus groups or mass surveys)

In response to the question: *"Should the government offer free mammography screening to all women aged 40-49?"* surveys would likely capture the prevailing public mood as to the importance of helping women access preventive health services rather than a nuanced view on the implications of lowering the age-related entry point for the national mammography screening program. In a CJ convened in Otago New Zealand to answer this question, which was comprised of women who had never participated in screening, almost all of the women had been in favour of mammography screening for women aged 40-49 at the start of the jury. However, by the end of their deliberations the CJ voted 10 to 1 against the proposal to lower the entry age because of the potential for harms and the lack of evidence of lives saved in that age group.<sup>10</sup> (Table Example #1)

CJs also highlight public values and social concerns that are not part of the evidence-base, but nevertheless could be of great importance to policy implementation. For example, two CJs comprised of Australian women aged 70-74 (Table Example #3) voted to retain invitations to participate in mammography screening services for their age-group, explicitly placing a low priority on the potential for overdiagnosis in their decision-making.<sup>11</sup> The reasons the jurors provided show how organised preventive health services have great symbolic value once established, and epidemiological evidence of an unfavourable balance of benefit to harm may not be enough to convince people of the need for discontinuation.

Although independent evidence-based expert advice on population screening is essential, good policy also relies on public trust. Through their exposure to evidence and expert opinion, the participants in these CJs about mammography understood that for population screening services to be effective there needs to be tolerance for some level of overdiagnosis. The women's tolerance level however appeared to be higher than that of the clinical research experts who were advising against screening. The benefits of screening, as well as the harms of screening-related overdiagnosis are experienced by otherwise healthy people. For reasons of transparency and accountability the values and priorities of potential service users should be considered and addressed in guideline development and program implementation.

### **Choosing jurors, types of evidence, and framing jury questions**

The policy relevance of a CJ convened to address an important issue such as overdiagnosis will depend on three important factors: how the topic or question is posed; who sits on the jury and how they are recruited; and the engagement of policy decision makers.

#### *Framing a question for the jurors to address*

In the CJs we have conducted on screening and overdiagnosis the question, expert witnesses, and the evidence presented to jurors were determined by a steering committee comprised of

neutral experts, and representatives of stakeholders from each side of the existing debates. The committee, organisers and expert witnesses worked together to ensure that the question put to jury was framed as 'neutrally' as possible so that the verdict was less likely to be subsequently dismissed. The quality and reputation of the experts who provided the testimony, and the structured process through which they reviewed and moderated one another's presentations helped to ensure that all views presented to jurors were relevant, and could be argued from the evidence.

Not every issue is suitable for deliberation by a CJ. Broadly speaking CJs on screening and overdiagnosis have addressed two somewhat different but overlapping policy questions: those that explicitly focus on resource allocation (Example #1), and, those about which policy options are most justifiable and perceived to be legitimate (Examples #2-5).<sup>12</sup> CJs are most useful for public engagement when the policy options require a deep consideration of both values and evidence.<sup>13</sup>

#### *Juror characteristics and the type of evidence produced*

CJs construct a form of mini-public, such that composition of participants will determine what kind of claims about 'representativeness' can be made about outcome. Three CJs held in Sydney Australia on PSA testing and overdiagnosis risks illustrate the difference between CJs composed of 'targeted' versus 'general' publics (Example #4).<sup>14</sup>

One of the CJs was comprised of men of screening age (potential PSA test users) and two were comprised of participants of mixed genders and ages. All prioritised allocating resources to support GPs to adopt an active role in supporting individual men to make decisions about PSA. However, in Sydney the two CJs comprising a range of citizens wanted all the information on potential harms and benefits of PSA testing to be provided to men before they took the PSA test. Whereas the all-male CJ of potential PSA test users did not want men burdened with uncertain and detailed information about risks associated with diagnosis and treatment until they had an adverse test result. This example illustrates how a jury comprised of service-users can provide a different perspective and insights into a different recommendation to that of a jury comprised of members of the public who may not be directly affected by the outcome.

The findings of juries comprised of service users provide insights into what changes to the status quo are likely to be acceptable to those affected. Juries comprising a broader range of citizens tend to reveal broader considerations, including the range of issues that may be important for weighing the fairness of resource re-allocation against a background of competing priorities.<sup>8</sup>

#### *Involvement by policy decision makers*

The CJs described in Table 1 were researcher-initiated but all involved clinical and policy stakeholders as expert witnesses and/or members of the steering committee. Public deliberation aimed at informing policy decisions around overdiagnosis should ideally involve the decision makers in the design or implementation, and a subsequent process of 'translation'

or knowledge mobilisation may be required.<sup>15</sup> This is not to suggest that decision makers who engage with CJs should be bound by the jury verdict, or that CJs cannot be legitimately done purely as research. But CJs are more likely to inform policy decisions if those involved recognise the value, role and limitations of the jury outcomes in larger political processes.<sup>16</sup> Individual clinicians and healthcare managers practicing in the field considered by a CJ may also find value in such research as a form of synthesis of the diverse values that patients may consider when weighing up screening decisions.

### **Informing policy aimed at addressing overdiagnosis**

Where expert opinion and public opinion diverge, CJs are valuable for understanding why and potentially informing future decisions about public communication and service delivery requirements to address patient concerns. The provision of factual information, exposure to well-reasoned and sometimes opposing expert opinions, and commitment to working through persistent disagreements (rather than dismissing them as deficits in understanding) can help to rebalance the information gaps about overdiagnosis and the discrepancy of power between experts, decision-makers and the community affected.<sup>18 19</sup>

As an authorship team, we have between us conducted more than 15 citizens' juries, several of which have considered overdiagnosis.<sup>11 14 20-22</sup> A consistent observation has been that members of the public report great surprise at the level of uncertainty embedded in medical practice. And particularly how new technologies / medical tests can create more uncertainties, rather than resolve concerns. Most people in high income countries like Australia are encultured to trust medical tests and trust their doctors.<sup>23</sup> They believe that doctors know the 'right' thing to do.<sup>24</sup> Trust in their doctors is inevitably the resource that people draw on when decisions need to be made in conditions of conflicting or uncertain evidence. CJs enable them to pull back the curtain on medical evidence and thus engage more meaningfully in screening policy debates. In our experience, during deliberations people first looked for the embedded interests that could drive apparent differences in expert opinion. But ultimately most jurors came to both understand and feel sympathy for GPs and other care providers who must manage medical uncertainty on a day-to-day basis.

### **Conclusions**

If done well CJs are an effective means to conduct research that inform guideline development for population screening and disease threshold determination.<sup>12 25</sup> Much could be achieved to address the social and ethical dimensions of overdiagnosis if those charged with organising and regulating these processes made a commitment to formally consider the values and preferences of well-informed members of the public and understand the complex trade-offs entailed. Procedurally CJ are explicit about the limits of medicine and the pervasiveness of medical uncertainty. This fits with the basic tenets of EBM,<sup>26 27</sup> and offers an authentic means to address the risks and benefits of screening, and issues related to overdiagnosis.<sup>28</sup> In addition, CJs potentially uncover how health services have other forms of value to the public, which need to be explicitly addressed and accounted for in the implementation of policy.<sup>29</sup> Bringing

the public into deliberation about overdiagnosis can broaden and improve the dialogue and make the reasons for decisions about resource allocation and potential withdrawal of services more clear and transparent, thus promoting public trust and partnerships at a time when trust in science and medical expertise appears to be in decline.<sup>30-32</sup>

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All authors have completed the Unified Competing Interest form (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work

### **Details of Contributions:**

All authors contributed to the conceptualisation of the paper. CD led the drafting of the paper, with substantial contributions from RT and LR. All authors commented and contributed to the revision of the final submitted version. CD is the guarantor of this paper.

### **Transparency declaration:**

The lead author affirms that the manuscript is an honest, accurate, and transparent account of the studies being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Ethical approval: Not required

### **Funding:**

This work was supported by NHMRC CRE 1104136 and NHMRC Program grant 1106452. The funder had no role in the conceptualization and drafting of this paper, or the decision to submit for publication.

### **Data sharing:**

There is no further data available for sharing

## **Key Messages**

- Overdiagnosis challenges the social contract that underpins healthcare, and community voices are often missing from the relevant policy discussions.

- Citizens/Community Juries (CJs) elicit the voices, values and preferences of informed citizens who are presented with evidence-based expert views, which the jurors deliberate among themselves before formulating their opinions and recommendations.
- CJs are an effective means to study public values that can be used to inform policies and practices to manage the risks of overdiagnosis, and to contribute to guideline development and proposed changes to disease thresholds.
- CJ processes align with the basic tenets of EBM, and can broaden and improve the dialogue around medical uncertainty, thus promoting public trust and partnerships at a time when trust in medicine is declining.

### Textbox 1: The characteristics of citizens' juries (CJs)

First developed by the Jefferson Centre in 1970s, CJs have been used to address issues such as reproductive technology, xenotransplantation, biobanking,<sup>8 13 25</sup> and on overdiagnosis.<sup>10 11 14 20</sup> There are a number of different CJ approaches but at a minimum, a group of 12-15 people are selected to meet over 2-4 days to consider and respond to a specific question. It is an issue, rather than an individual, that is "on trial".<sup>33</sup> All CJs have two phases: the first focuses on educating participants, the second on deliberation. During the first phase jurors are provided with balanced factual information from expert witnesses (of whom they can ask questions and seek clarification), such that a diverse range of potentially conflicting perspectives are considered.<sup>25 34</sup> Drawing on the evidence presented, during the second phase the group work together in facilitated session to produce a verdict or set of recommendations.. CJs create the conditions for people to move beyond superficial arguments and suspicion of vested interests to understand the complexity of medical decision making, and then reflect on their own values and what is important to their communities. Consensus is encouraged but not essential; dissenting views and minority positions are included in the final report.

What distinguishes deliberative methods from other forms of public engagement is a process of iterative two-way exchange between representatives of the public and the deliberation sponsor (researchers, government or other agencies). In theory, the deliberative process informs and extends participants' thinking beyond their own interests to consider the collective needs of the community and common or public goods. Like all engagement methods however, CJs have been subjected to critique.<sup>35-38</sup> The most common concerns are about the representativeness of the selected group and whether a group of lay-people can overcome deficits in expertise to make judgements that truly reflect their values and informed preferences. It is important to recognise that CJs of 12-24 people cannot possibly represent a statistically characterised sample of 'the general public' or the prevalence of views. Rather, they offer insights into how and why informed citizens prioritise concerns about complex issues like overdiagnosis, and provide explanations for divergence in opinions. CJ participants should be recruited to capture diversity of experiences and backgrounds in a community, and the deliberation processes organised so as to redress power imbalances as much as is feasible.<sup>39</sup> When conducted in this way, CJs can reveal and capture key community concerns and arguments about current / proposed policy directions and enhance accountability in decision-making.



**Table 1:** Key issues and questions pertinent to Overdiagnosis that have been addressed by Citizens/Community (CJs) Juries in Australasia

Key Issue	Sponsors of and reasons for the jury or juries	Question put to the jury or juries / Jury characteristics	Verdict(s)	Novel insights
Should governments fund cancer screening services for populations at higher risk of Overdiagnosis	<u>Example #1</u> Convened by health researchers in New Zealand to explore the use of CJs to inform the development of population screening policy.	<i>Should the government offer free mammography screening to all women aged 40-49?</i>  1 jury (n=11); all-female aged 40-49, with no previous diagnosis of breast cancer.  [See REF 10 for more details]	The jury voted (10-1) against government provision of mammography screening to this age group	Conducted in 2008, this jury established the viability of the CJ method to engage members of the public in deliberations about how to manage Overdiagnosis. Women who were almost all initially in favour of screening for women aged 40-49 changed their minds because of the potential for harms and the lack of evidence of lives saved in this age group. The findings revealed how women weighed the benefits and harms, and how withdrawing an existing service is more challenging than not offering it in the first place.
What are the values and priorities that should guide decision making around the promotion of participation in screening services	<u>Example #2</u> Convened by health researchers in Australia and funded by the National Health & Medical Research Council (NHMRC) to examine informed men's views about the benefits and harms of PSA testing. Also established to further examine the value of CJs for informing screening policy.	<i>Should government campaigns be provided (on PSA screening) and if so, what information should be included in those campaigns?</i>  1 jury (n=11); all male aged 50-70, with no previous diagnosis of prostate cancer [See REFS 20 & 22 for more details]	The jury voted unanimously against government information campaigns, and against an invitation program for PSA testing.  Instead the CJ proposed a campaign targeting GPs to assist them to provide better quality and more consistent information to their patients.  Men's unanimous agreement on information provided by Governments and GPs contrasted with the diversity in men's individual preferences on whether or not they get screened themselves.	Men prefer to get information about PSA screening directly from their GPs. There was significant concern about the discrepancy and variability in quality of the information available to men, and that some GPs were currently not following evidence-based guidelines.  The study illustrated that informed publics are clearly able to distinguish between personal preferences, and deliberating to formulate recommendations regarding a public good.  A quantitative analysis of the same study demonstrates that expert provision of information altered CJ participant's intentions to screen compared with written information from Cancer Council Australia and Andrology Australia.
	<u>Example #3</u> Convened by health researchers in Australia and funded by the NHMRC	<i>Should the organized breast cancer screening program continue to <u>invite</u> and promote screening to</i>	Both community juries of women aged 70-74 found by a majority verdict (16-to-2 and 10-to-6) that invitations to participate in screening	These women valued being invited to screen: invitations were thought to provide an opportunity to access information to enable choice, and to demonstrate that society

	<p>to elicit the informed views of older women on the acceptability of ceasing to invite them to use breast cancer screening services</p> <p>Contributions from the Cancer Council of Australia.</p>	<p><i>women 70-74 without cost to participating women</i></p> <p>2 juries (n=34); both all-female aged 70-74, with no previous diagnosis of breast cancer [See REF 11 for more details]</p>	<p>should continue to be sent to women in their age group.</p>	<p>recognised and supported older citizens. Evidence that an intervention potentially does more harm than good may not be enough to convince people to give it up: the study revealed other values people may consider important, such as older women being valued and continuing to be offered the same options and choices as younger women.</p>
<p><b>How should care-providers and asymptomatic patients manage the risks of Overdiagnosis at the point care</b></p>	<p><u>Example #4</u></p> <p>Convened by health researchers in Australia and funded by the NHMRC to elicit the informed preferences of citizens and potential service users as to how PSA testing of asymptomatic men should be managed in general practice</p> <p>Contributions from the Prostate Cancer Foundation of Australia.</p>	<p><i>Should GPs introduce the topic of PSA testing during appointments with male patients who have no symptoms? Or should they wait until men ask about it?</i> <sup>14</sup></p> <p>3 juries (n=40) - 2 of mixed genders and ages and 1 all male jury aged 37-74 with no participants with an experience of a prostate cancer diagnosis  [See REFS 14 for more details]</p>	<p>In contrast with the Royal Australian College of General Practitioner guidelines, all juries concluded (by majority vote) that GPs in Australia should initiate discussions about PSA testing with asymptomatic men over 50.</p>	<p>While GPs might resist raising questions about PSA testing, an informed public prefers them to take on this responsibility because in Australia there is already so much divergent advice in the public sphere – and doctors are perceived as the best placed inform and explain the risks and benefits. Juries consistently agreed that discussions with their GP was better than men relying on finding out (or not) about the PSA and the risks of Overdiagnosis from other sources.</p>
	<p><u>Example #5</u></p> <p>Convened by health researchers in Australia and funded by Bond University to explore informed community perspectives around current Australian GP practices of case-finding for dementia</p>	<p><i>Should the health system encourage General Practitioners to practice “case-finding” of dementia in people older than 50?</i></p> <p>1 jury (n=10); mixed genders aged 50 to 70; with no participants (or their immediate family) with an experience of Alzheimer’s, Mild Cognitive Impairment diagnoses or caring for an individual with these diagnoses.  [See REFS 22 for more details]</p>	<p>In contrast with the Royal Australian College of General Practitioner guidelines, the jury voted unanimously against “case-finding” for dementia by GPs. Participants cited lack of effective treatments, potential to negatively impact mental health. Although they disagree with “case-finding” as it was currently practiced, CJ participants drafted a set of recommendations to improve future guidelines.</p>	<p>CJ participants decided to go beyond the CJ question and suggested alterations to the RACGP guidelines in an attempt to reduce potential harms of current ‘case-finding’ practices.</p> <p>As above, the study indicated that an informed public may have different priorities than those assumed in the clinical guidelines.</p>

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